

Volume 4, Issue 9

# MOTIVATED

THE MAGAZINE THAT MOVES YOU!

**JOY**

**Heaven's Very Special Child**

**Parenting from the Heart**

Teaching your child about peers with special needs

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Issue Editor

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Christina Lane

Design

awexdesign.com

Contact Us:  
Email  
Website

motivated@motivatedmagazine.com  
www.motivatedmagazine.com

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Just as I sat down to write the editorial for this issue, a friend posted a link to what he called, "some good news for the day." It was a video clip of a teenage basketball player with autism, who, after being an assistant to his high school basketball coach for a year, is given a chance to play in a game. He not only rises to the occasion, but also ends up scoring baskets multiple times, to the amazement of his coach and teammates. As he is carried off on the shoulders of his teammates amidst cheers and hollers, the CBS commentator finishes the story with, "Because he has autism, Jason is used to feeling different, but never *this* different, never *this* wonderful!"

This moving story got me thinking that even though most people are tolerant and accepting of those who are different, there is still much prejudice toward people with disabilities. At the core of prejudice is the thinking that everyone should for the most part be the same, think the same, respond, and behave the same. But when we get beyond that, and realize that the way God creates life is diverse and individual, then we learn to not just tolerate and accept, but appreciate differences in others.

This issue of *Motivated* highlights how unique and precious each person is—regardless of their abilities. I hope it will help create awareness, and inspire not just tolerance, but true appreciation of individuals who face challenges. If we can look beyond their differences to the potential within, and like the basketball coach, create opportunities for them, we might start hearing a lot more "good news" stories—like the one about Jason, the basketball player with autism.

Christina Lane  
For *Motivated*

# Heaven's Very Special Child

By Edna Massionilla, adapted

A meeting was held quite far from earth,  
"It's time again for another birth,"  
Said the angels up in heaven above,  
"This child will need much love."

"Her progress may seem very slow,  
Accomplishments she may not show.  
And she'll require extra care,  
From folks she meets way down there.

"She may not run or laugh or play,  
Her thoughts may seem quite far away.  
In many ways she won't adapt,  
And she'll be known as handicapped.

"Her parents may not realize right away,  
The leading role they're asked to play.  
But with this child sent from above,  
Come stronger faith and richer love.

"And soon they'll know the privilege given  
In caring for this gift from heaven.  
Their precious charge, so meek and mild,  
Is heaven's very special child."





# Joy

By Jackie, Web Reprint

If I could choose only one word to sum up Gina, my daughter with Down syndrome, it would be “joy”! I know that it might sound strange to choose the word “joy” to describe a child with a disability, but I choose to focus on the joy she brings and not the fact that she has an extra chromosome, which causes developmental delays. I have learned—better yet, my daughter has taught me—that taking a little longer to develop has some redeeming qualities, and taking life at a slower pace has a lot to offer. It has been a valuable lesson that I might have never learned had it not been for Gina.

Thinking back to the time of Gina’s birth, the day that we were confronted with the news she had Down syndrome, I have to be honest and say that “joy” was not my initial reaction. In the

beginning I could not feel the joy this new child offered. I was filled with fear and sadness. I worried about the future, and my mind was flooded with questions. How would we manage? How would our family handle the news? What kind of financial burdens were in store for us? Would people make fun of her? Would she be able to go to school? There were so many unknowns. I was numb and confused. I felt as if there was a heavy blanket of fog lying on top of me. At the time, the weight of all this was crushing, and “joy” could not work its way to the surface. I wish that I could go back to the time of her birth and change the initial thoughts that came to my mind, but they were all part of the process of grieving for the child that I expected and the beginning of accepting the “joy” that was to come.

The days that followed were full of cardiologists, geneticists, phone calls, research, and neonatal intensive care hospital visits. Life was a blur. We needed time to cope with the news. We brought her home, and it wasn't long until the blanket of fog began slowly to dissipate—lifted by so many hands along the way, the hospital staff, doctors, wonderful caring friends and family. I learned about the valuable support from the *National Association for Down Syndrome* and began connecting with other parents of children with Down syndrome through their Parent Support Program.

Being able to talk to someone who understood what I had experienced and knew the answers to so many of my questions was very comforting. They willingly shared their wisdom, taught me about early intervention, and showed me a wonderful community of support that was already in place. I have learned many life lessons, and I truly value the support that has come from those who have gone before me. I found my spot in that community and have learned to share, laugh, and love all the children

with Down syndrome I have met.

Those initial fears we had in the hospital room have come and gone. We have managed well, and the financial burdens are minimal. Our children, family, and friends handled the news just fine, and they celebrate each of our daughter's accomplishments as if it were their own. At school, she is supported in a regular classroom and has an incredible team that assists her to achieve her maximum potential. Most of all, she is accepted by the community. I have not experienced anyone making fun of her, and if they did, they wouldn't be anyone I would care to know. In fact, many people say hello, call her by name, give her a thumbs up or a high five. I might add that many of these are people we have never been formally introduced to! She has been able to create her own identity, and her joy spreads beyond our family home.

We cherish each moment she brings us, and life is a wonderful adventure, even with Down syndrome. We have learned that those initial fears were nothing compared to the love and “joy” that we have gained from her life! ▣

## What Is Down Syndrome?

Down syndrome is an intellectual disability that about 5,000 babies in the United States are born with each year. A person with Down syndrome has 47 chromosomes, microscopic structures that carry genetic information to determine almost everything about a person. Most people have 46 chromosomes. It's the extra chromosome that can cause certain physical characteristics (such as short stature and an upward slant to the eyes) and speech and developmental delays. Yet, people with Down syndrome are a lot like you: They are unique people with strengths and talents.



# Cerebral Palsy: Keith's Story

Web Reprint, excerpts

## Apparently, having cerebral palsy makes me different.

I've had cerebral palsy since birth and I'll have it until I'm old and gray. There isn't a day that I'm not reminded I have the condition. And there never will be a day I won't have it. But in my mind's eye, life is good: If anything, cerebral palsy has made me a stronger, more humble person. I can even say having cerebral palsy has contributed to my success.

I'm in college now. As a teen with CP it was easy for me to get overlooked, discouraged, or even patronized simply because I wasn't considered "normal." This became especially apparent when doctors began prescribing "special devices" to help me re-establish or maintain a "suitable range of motion." These devices were to be worn while doing everyday activities, including school-time activities.

Because my CP mostly affects my legs and the way I walk, I had to wear knee-high, white-plastic, custom-made leg braces at all times during my first couple

of years of high school.

Laced with Velcro, these braces locked my ankles and heel cords in a fixed position. Needless to say I hated those braces! They were painful, noisy—thanks to the Velcro and cheap plastic—and they seemed to broadcast that I was "crippled" (my skin crawls when I hear that word).

## I'm rubber and bullies are glue

As mild as my case of CP may be, there were always the high school bullies who found pleasure in bringing me down. Sometimes it felt that the only reason they were in school that day was to be my rain cloud, following me around pointing out my mistakes and flaws.

My bullies were girls as well as guys. They weren't physically threatening. They were the kind who hurt with words or by forcing an embarrassing situation, constantly looking over a shoulder for supporting chuckles from friends. However, my bullies normally found themselves laughing alone, because I'd

already beaten them to the punch line. I was well liked, so the joke was on them. The reality was they had a lot of catching up to do.

A bully can't compare to what you put yourself through mentally. Just entertaining the thought that you're not the same as everyone else can work against anyone, even when you know you're above the norm in so many ways. During school, I never wasted time worrying what other people thought of me. I mostly worked on staying positive and meeting my own standards and expectations.

But there were times when people really got to me—their harassing, hurtful words began to penetrate. A couple of times, I even caught myself thinking, “What if they're right?” I found this the hardest place mentally to pull myself out of, but I told myself what I knew to be true: “It doesn't matter what they think, you know you're better than them simply because you don't resort to acting like them.” I found it didn't do any good to avoid the people who put me in these mental dark places. Instead, I worked on beating them to the punch line, turning the joke on them. This

helped me develop a great life skill: the art of the witty comeback.

## Spastic about sports

The same theme of having a positive attitude can be applied to cerebral palsy and sports. I played many sports while I was in high school, but I was best at golf. Go figure: the one sport that requires balance and precision—two weapons that aren't readily available in my arsenal. But I really excelled at golf.

In my experience, people tend to admire you most for trying. They want to see you succeed, sometimes more than succeeding themselves. Four years of varsity golf was one of the highlights of my high school career.

Whether I'm winning or losing, young or old, I will always have CP. That will make me different from everyone else, but it is up to me to decide how differently I present myself. For me, CP is not an excuse for bitterness or negative actions, but a reason to better myself—an excuse to try harder and be more successful.

Life can try to play a joke on you, so why not beat it to the punch line? ▣

## What Is Cerebral Palsy?

Cerebral palsy (CP) is a disorder that affects muscle tone, movement, and motor skills. CP is usually caused by brain damage that occurs before or during a child's birth, or during the first 3 to 5 years of a child's life. This brain damage can also lead to other health issues, including vision, hearing, and speech problems, and learning disabilities. There is no cure for CP, but treatment, therapy, special equipment, and, in some cases, surgery can help a child with CP.



# Autism Breakthrough: Carly Fleischmann's Story

By Callie Carmichael, CNN, adapted excerpts

Carly Fleischmann lived most of her childhood trapped in a body that could not communicate clearly with the outside world.

She couldn't speak and had few fine motor skills. She'd been diagnosed with severe autism at age 2.

Even with the progress that has been made with therapy techniques and medication, Carly was still a mystery to her own family. Who was she? What would her voice be like if she could speak? These were all questions that would go unanswered until she began to type.

One day, during a session with one of her therapists, Carly began to feel sick. Unable to speak to convey her condition,

she went out on a limb and took the keyboard. She typed "Help teeth hurt." This would be the breakthrough that eventually allowed her to communicate with the outside world.

A life without smart phones and other mobile devices would be hard to imagine for those of us who are phone-clutching, tablet-wielding mobile device addicts. How would we be able to live without Facebook or Instagram always in our pockets? How could I check my bank account balance while I'm out shopping? But for Carly and many others like her, these devices give so much more: a voice.

The first-generation iPad was released in the U.S just after Carly's 15th

birthday. Her family immediately drove from their home in Toronto to purchase one. They knew that the iPad would be a turning point for her to have freedom and the ability to communicate like never before.

As Carly began to type more, her family and her therapists got to know her. She was a sharp-witted, bright girl who knew pop culture. She cracked jokes and poked fun at her brother, complaining about his teenage boy smell. She had her own sense of style. But most important, Carly was tenacious. She made it clear that she was willing to fight to achieve her goals.

Before the iPad, she tried several mobile communication devices. These tools had text-to-speak functionality, but she didn't really take to them.

“She rejected her early communication devices like the Lightwriter and the DynaVox because she felt they made her

look disabled,” her parents said. “She doesn't think of herself as disabled; she thinks of herself as a kid with autism. But she doesn't want that to define her.” The iPad was a game-changer for Carly, and because it was deemed “cool,” it did not make her feel different.

Carly says she loves her iPad and says, “thanks to it, I participate in class in a whole new way.”

Carly and her father have written a book, *Carly's Voice*, detailing her struggles and triumphs with autism. Her dad says that while Carly may not have the fine motor function to do things like tie her shoes, he hopes she will be able to attain more independence through technology.

Carly says her next goal is to attend university. She has her eye on UCLA and says she wants to get her bachelor's or her doctorate like her idol, Temple Grandin. ▣

## What Is Autism?

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors. Autism appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between 2 and 3 years of age. Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 88 American children as on the autism spectrum—a ten-fold increase in prevalence in 40 years. Studies also show that autism is four to five times more common among boys than girls.



# Teaching your child about peers with special needs

By Deborah Elbaum, M.D., adapted

## Disability awareness, compassion, and making friends in the classroom

According to her mother, 8-year-old [Jasmine] is “really sweet and loves attention.” She goes to her friend’s house, does horseback riding, and likes to play board games. She also has cerebral palsy, and is non-verbal and non-ambulatory. She uses enhanced communication devices to communicate, and a wheelchair for mobility. At her public school, [Jasmine] has a one-on-one aide and spends time both in and out of her third grade classroom.

Disabilities cover a wide range. Some are obvious—such as a child with a physical disability who uses a wheelchair, or a child with a visual impairment who uses a cane to navigate when walking. Other disabilities may be more “hidden”—for example, children who have learning disabilities or autism spectrum disorder.

Chances are that at some point your child will have a classmate with a disability. Just as you guided your very young child when he or she began to befriend others, you can encourage your

child to learn about and be a friend to children who have special needs.

### Basic ideas to share with your child

- ❖ No two people are the same—some differences are just more noticeable.
- ❖ A disability is only one characteristic of a person. People have different likes and dislikes, and diverse strengths and challenges.
- ❖ Children with special needs are like you and all children in that they want friends, respect, and to be included.
- ❖ Children can be born with special needs or become disabled from an accident or illness. You can’t “catch” a disability from someone else.
- ❖ Just because someone has a physical disability (when a part or parts of the body do not work well) does not mean they necessarily have a cognitive (or thinking) disability.
- ❖ Children with special needs can do many of the things you can do, but it might take them longer. They may need assistance or adaptive equipment to help them.

Try to use clear, respectful language when talking about someone with special needs. For a younger child, keep explanations simple, such as, “She uses a wheelchair because a part of her body does not work so well.”

Reinforce with your child that name-calling—even if meant as a joke—is always unacceptable as it hurts people’s feelings.

## Getting to know children with special needs

Paradoxically, when it comes to approaching someone with a disability, children may be better at it than their parents because they are less inhibited. Some adults—especially those without previous exposure to people with special needs—may be more timid. Worried about appearing intrusive or insensitive, they may not know what to say or do.

“The other kids are great,” [Jasmine’s] mom says, “They are very direct, which is good. They like her and want to interact with her.”

However, if your child (or you, for that matter) is unsure about approaching

a child with a disability, here are some helpful tips:

- ❖ Most parents of children with special needs would prefer that other adults ask them about their child directly, rather than avoid them. A smile or friendly “Hello!” is an easy icebreaker.
- ❖ Even if a child doesn’t talk, there are still activities the children can do together, such as play board games or arts and crafts.
- ❖ If your child wants to have a play date with a child with a disability or invite him or her to a birthday party, encourage it. Call the other parent and say simply, “How can we make this work?”
- ❖ Share any concerns with the other parent. Parents of children with special needs will often be happy to facilitate a successful play date or outing.
- ❖ Extra effort goes a long way. For instance, learning simple signs so that you can better communicate with a child who is deaf (and uses sign language) will be much appreciated. □

## Learning more about special needs

Reading or learning about a disability is a great way to further understand a child’s experiences. It may also help dispel any questions you or your child may have. Your local library and librarian can be a great resource for finding age-appropriate books and materials.

Deborah Elbaum, M.D. is a parent of three children and lives in Massachusetts. She is a volunteer for the disability awareness program taught at her children’s school.



# The Beauty of Diversity

Strength lies in differences, not in similarities.—Stephen R. Covey

We need to give each other the space to grow, to be ourselves, to exercise our diversity. We need to give each other space so that we may both give and receive such beautiful things as ideas, openness, dignity, joy, healing, and inclusion.—Max de Pree

I have a disability, yes, that's true, but all that really means is I may have to take a slightly different path than you.

—Robert M. Hensel

It is not our differences that divide us. It is our inability to recognize, accept, and celebrate those differences.—Audre Lorde

Human diversity makes tolerance more than a virtue; it makes it a requirement for survival.—Rene Dubos

If the world thinks you're not good enough, it's a lie, you know. Get a second opinion.—Nick Vujicic

Disability is a matter of perception. If you can do just one thing well, you're needed by someone.—Martina Navratilova

We need to reach that happy stage of our development when differences and diversity are not seen as sources of division and distrust, but of strength and inspiration.—Josefa Iloilo

We all should know that diversity makes for a rich tapestry, and we must understand that all the threads of the tapestry are equal in value no matter what the color.—Maya Angelou

Diversity is not about how we differ. Diversity is about embracing one another's uniqueness.—Ola Joseph

